MyChildren's: Integration of a Personally Controlled Health Record with a Tethered Patient Portal for a Pediatric and Adolescent Population

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Abstract

Personally controlled health records (PCHRs) and patient portals are increasingly being offered by healthcare institutions, employers, insurance companies and commercial entities to allow patients access to their health information. Both applications offer unique services to provide patients with tools to manage their health. While PCHRs allow users ubiquitous, portable, patient controlled access to their health information, traditional patient portals provide provider-tethered applications allowing patients access, but not control of, certain healthcare information, as well as communication and administrative functions, such as secure messaging, appointment management and prescription refill requests, facilitating care at a specific healthcare facility.

We describe our approach for the design, content creation, policy development, and implementation of MyChildren's, a unique web-based application leveraging the advantages of both a provider-tethered patient portal and a PCHR to allow patients and their guardians access to the functionality and convenience of a traditional patient portal, as well as the portability and flexibility of a PCHR.

Background

Patient portals and personally controlled health records (PCHRs) are gaining traction among healthcare institutions, employers, insurance companies and commercial entities alike as mechanisms to improve the safety and quality of health care delivery, as well as modalities to activate and involve patients to a greater degree in managing their own health (1-9). There is great variation in the features and functionality of available patient portals and PCHRs. Most tethered patient portals allow patients access to select health information from a single institution, and enable them to perform certain administrative tasks, such as appointment management and prescriptions refills (9-10). Data are controlled by the portal provider, and patients can only access the site as long as they have an active relationship with the institution supplying the portal. There are three PCHR platform providers currently. Indivo (used by the Dossia consortium, which includes Wal-Mart, Intel, AT&T, and five other companies)(6, 7), Microsoft and Google(11). PCHRs provide ubiquitous, portable, patient-controlled, lifelong access to health information and are capable of aggregating data from multiple sources. To date, core PCHR functionality does not include the ability to manage appointments, or to request referrals or prescription refills, as such features have tended to be specific to an institution or provider. We describe our efforts in creating MyChildren's, an application that seamlessly integrates a provider-tethered portal with a PCHR (the Indivo open source PCHR, developed at Children's Hospital Boston over the past decade) in a pediatric tertiary care center, in order to provide patients and their families the features and benefits of both.

Methods

We convened a multidisciplinary team including senior representation from information services, research informatics, general counsel, medical records, compliance, public affairs and clinical leadership at Children's Hospital Boston (CHB) to create and implement MyChildren's, a unique web-based application that contains features available in traditional patient portals, as well as an embedded PCHR, Indivo, developed at Children's Hospital Boston(12, 13). This team was involved in the design, creation and implementation of MyChildren's. Specifically, the group discussed and created the registration process for account creation, content of the application, as well as policies involving access and handling of the data. Careful consideration was required in addressing the data requirements of both a traditional portal, which is controlled by the institution, a PCHR, which is personally controlled, and the unique legal, developmental and ethical needs of the pediatric and adolescent patient population for whom MyChildren's is being deployed(14). An important criteria that was used when evaluating each step of the implementation was to "do no harm"; although we wanted to give access to as much of the patient's health information as possible, we did not want to do so at the risk of disclosing sensitive information, or of disclosing information to an inappropriate party.

Results

MyChildren's can be accessed by logging onto www.MyChildrens.org. Guardians, adult patients, and select minor patients can gain seamless access to the functionality offered by both applications. The portal-specific functions include the demographics overview (including insurance information), secure messaging, appointment management and patient

billing. Access to patient health information occurs through the embedded Indivo PCHR. Data populating the various applications comes from multiple sources, including the hospital's electronic medical record system, the electronic registration and billing system, as well as patients and guardians themselves. In the future, additional non-CHB electronic data feeds will be handled by the PCHR, including data from the primary care provider's EHR systems, claims data from insurers, etc. Unlike traditional portals, where access is terminated upon a patient ending her relationship with the portal provider, the patient can maintain lifelong access and control of her health information through the Indivo PCHR.

Access and Account creation

Access to MyChildren's is obtained through a web-based registration process. This process creates both an account for MyChildren's, as well as a separate account for Indivo, in one seamless procedure. While the Indivo record can be easily accessed through MyChildren's with a single sign-on process, the creation of an additional, separate Indivo account ensures continued access to the PCHR, even after a patient may transition to a different provider and terminates her relationship with CHB. Guardians, adult patients, and certain minor patients can register for a MyChildren's account, based on age and developmentally appropriate policies. Separate accounts are created for each user, allowing accounts to be linked based on guardian-patient relationships. The registration process requires an email address and knowledge of information that only the patient and/or guardian should know. These include the date of the patient's last visit to CHB, the patient's CHB medical record number (MRN), or an account number from a recent CHB bill. This data can be obtained in person or by postal mail, but is not released over the phone or email, in order to guarantee that the information is not released to the wrong person. After entering basic personal information, including name, date of birth, and email, users are asked to supply a username and security question. An email is then sent to the user with a temporary password. After logging onto the MyChildren's site with their username and temporary password, users must respond to the security question, and provide the patient's address and MRN in order to proceed. Once this information has been submitted, an administrator verifies the identity of the user. In the case of a guardian, the relationship of the guardian to the patient must be confirmed prior to approving the account and allowing the child's record to be linked to her account. If there are any discrepancies in the information provided by the applicant compared to the information in the hospital's registration system, the applicant is contacted to notify her that she has not been granted access because of these discrepancies. These discrepancies can only be resolved in person by the applicant; for security purposes, phone and/or email resolution is not permitted.

Parents or guardians can link multiple minors to their account. Adult patients and adolescent patients between the ages of 13-17 may also register for an account. In the case of adolescent patients, they require parental consent to obtain access to general, non-confidential health information; access to confidential health information such as information involving reproductive health, sexually transmitted diseases, and drug use, does not require parental consent(14). Parental consent is obtained via a printable form that must be signed by the parent and returned to the hospital.

During the registration process, users can agree to grant authorized CHB clinicians access to their PCHR. If they allow access, providers can enter the patient's PCHR through an "Indivo" icon on the menu bar of the hospital's electronic medical record. If the patient has an account and has granted providers access, the patient's Indivo record appears in a new window. No additional log-in is required by the provider to access the PCHR. This unique single-sign on mechanism allows seamless access to both the patient's CHB electronic medical record and the patient's Indivo record, allowing a clinician a quick overview of all available information and potentially new information not contained in the CHB database. This system uses existing workflows, thereby encouraging providers to access the Indivo record at the point of care, without spending additional time logging on through a separate website and looking up the patient. No other PCHR we are aware of provides this valuable capability.

If a patient does not grant access to all CHB providers, she can invite individual CHB providers to gain access to the Indivo record as they would non-CHB providers, namely through the "sharing" feature in Indivo. This, however, requires the provider to hold an Indivo account and log in separately to access the patient's record through the Indivo website.

MyChildren's Features

Upon logging into MyChildren's, a drop down menu allows the user to select a patient she wants to access, in the case of a guardian who has access to more than one child's record. The home page provides an overview dashboard of all of the content, allowing easy navigation through the available features.

Demographics

The demographics tab permits users to update and edit their personal information, including address, insurance coverage, guardianship, primary care physician, referral requests, and details about race,

ethnicity, and religious preferences. This information is linked to and populated by the hospitals' electronic registration database and allows information that users edit within MyChildren's to be sent to a work queue, where the data is reviewed and updated in the hospitals' database.

Secure messaging

The secure messaging feature affords patients and their guardians secure electronic messaging capacity with any of the participating providers and clinics at CHB. Users can message individual providers with questions or, if the issue is of a more general nature, can send a message to a global email for the particular clinic. The secure messages are linked to the providers' hospital email accounts; providers are notified by email that they have a new secure message waiting for them, and are provided a web link in the message that allows them to log in to view and respond to the message. The email exchange between the patients/guardians and providers can be saved to the patient's medical chart if a provider so chooses, producing a permanent document of the correspondence in the electronic medical record. Given the variability in providers' use and comfort with email, providers can choose to create an automatic message linked to their secure messaging address which details how frequently they check email and how soon patients should expect to receive a reply. Similarly, the clinicians' out of office notifications that they set on their hospital email account are also automatically linked to the secure messaging system. A statement on the site alerts patients to the fact that urgent or emergent issues should not be discussed through secure messaging.

Appointments

Patients and/or guardians can manage clinic appointments through the appointments tab. Users can request, confirm, cancel or reschedule an appointment. Patients and guardians are furnished with an appointment history, and data fields for new appointments requests can be automatically populated based on a historical visit which is stored in the electronic registration database.

Billing

The billing tab allows guardians and patients to view billing information for each hospital visit. PDF's of their paper-based bill are also available here. In addition, outstanding balances can be paid directly online through a secure link to a commercial bank.

Indivo Health Record

Indivo is a PCHR that is embedded within MyChildren's, and replaces the health information feature of traditional patient portals. It contains a summary form, medication list, problem list, clinical information including laboratory results and selected documents, vital signs, immunization histories, growth charts, and the ability to share information with healthcare providers (both CHB and non-CHB providers), school nurses, family members, and other individuals involved in the patient's care.

PCHR data is populated by both electronic data feeds and manual user input. Electronic data feeds are made available through a "subscription agent", which allows users to subscribe or unsubscribe to various data sources. Currently data is only available from CHB clinical data sources, though other sources are planned for the near future. The subscription agent refreshes and adds new available data every 24 hours.

Content

A Bulletin board on the home page alerts patients to new policy updates, health messages, downtime and software upgrades. Updates to this page are handled by an administrator.

A summary page contains a snapshot of the patient's health status, including medication lists, problem lists, allergies, laboratory results, immunizations, recent vital measurements, and procedures. As data for this page can originate from multiple sources, including the CHB subscription agent, the user, or other subscription agents, unique icons identify the source of the data (Figure 1). The icon legend is available and readily accessible at the bottom of the page. Detailed information can be obtained by either clicking on the information from the summary page or by accessing the information from the side menu.

Figure 1. Indivo Health Summary Page

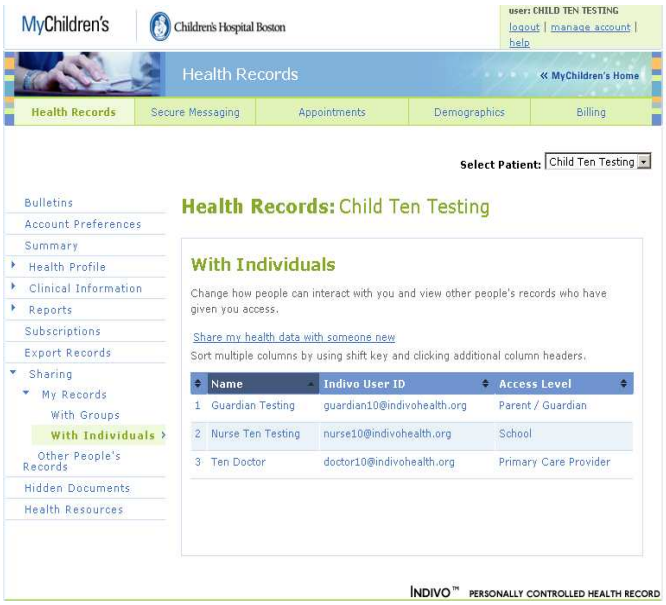
Patients and providers can also access various reports, including for example a printable school health form. The school form is populated by data from the electronic medical record.

Generic emails are sent to the guardian and/or patient when new laboratory results have been added to the

record. Details of the type or content of the result is not incorporated in the emails for privacy and confidentiality purposes.

Users may also share all or parts of their Indivo PCHR with others. By inviting providers, family members or others to create an Indivo account, they can allow these designated individuals to access their health information through Indivo, again leveraging the unique features of a PCHR. This allows providers who are not at CHB easy access to the patient's CHB laboratory results and clinical documents (Figure 2).

Figure2 Indivo Evite: Health Information Sharing



Data privacy and policy considerations

Given the unique architecture of the MyChildren's application, as well as the distinct needs of the pediatric and adolescent population, careful consideration of policies surrounding the release, control, and revision of data is required. Policies must handle the ethical, legal, and developmental needs of the pediatric population and take into account the various users controlling and accessing the record(14). Also, the information released to the PCHR reverts to the control of the patient and/or guardian, and thus complete transparency of how personal health information is handled is particularly important for a PCHR, to ensure privacy, confidentiality and reliability of the record's content.

Data feeds to the portal-specific features, including demographics, appointments; secure messaging, and billing permit data feeds back to CHB, essentially allowing both the MyChildren's data and the CHB database to be updated. However, the Indivo record only tolerates a unidirectional data feed. The subscription agent allows data to populate the Indivo record, but no information is sent back to the database or to a work queue. Given the nature of the information in question, this prevents the risk of data corruption in the hospital's database, should erroneous information be added to the Indivo record, and also allows providers the opportunity to review discrepancies between the Indivo record and EHR.

Currently, the CHB subscription agent releases data from outpatient encounters only. No inpatient or emergency department data are available for release at this time. Given the volume of inpatient data and the questionable utility of releasing serial laboratory results and vital signs which mostly serve a purpose during an acute hospitalization, we chose to limit the data feeds to outpatient only data. Future studies will need to determine what relevant data should be released from inpatient and emergency visits. The outpatient encounter data includes allergies, vital measurements, immunization histories, non-confidential laboratory results, and clinical notes from select clinics. Laboratory results and clinical notes are released 24 hours after they become available in order to allow providers to review the data should personal communication of the results be more appropriate and to allow a window for erroneous data to be corrected prior to being released to the PCHR.

Appropriate users may edit data fields within most of the portal-specific features, but only select information can be edited in the PCHR. Only guardians and adolescent patients may edit, void, annotate or hide information in the PCHR. All other users have "read-only" permission. Medication lists, problem lists, procedure lists, and allergy lists can be edited. Any editing creates a permanent document history, including the username and timestamp. Erroneous medication and problem entries can be voided, but are still accessible for review and are never permanently deleted. This is particularly important in a pediatric PCHR, as multiple users can have editing and voiding privileges.

Laboratory results and clinical documents, such as notes or radiology reports, cannot be edited or voided by any user. Annotations or notes can be added by users if an error is detected. However, if a document is erroneously released to a patient's PCHR, such as another patient's clinical note or laboratory result, the system administrator can retract that document without the patient's or guardian's permission to ensure patient privacy is maintained. To preserve complete transparency, a notation will remain in the patient's PCHR regarding the in-error document retraction.

Patients and guardians are also permitted to hide selected medications, problems, documents or results. If users choose to hide information, the particular

information is not visible to any other user who has access to the PCHR. Users can "unhide" the data at any time.

Deployment and Evaluation

MyChildren's was initially made available in pilot form over the course of a year in several subspecialty programs at CHB, with a hospital-wide release in late April 2009. Within 3 months after full deployment, there are 929 active MyChildren's accounts, representing 403 parent accounts and 526 patient accounts. The mean patient age is 9.4 years (±7.4 yrs). Users have logged into their accounts an average of 6.3 times (SD ± 15) since deployment. The Indivo PCHR was accessed during 82% of these logins. The most frequent Indivo PCHR feature accessed is the lab results section (82%), followed by the summary form (21%). Additionally, patients or their guardians have viewed, added or edited their medication list (5.4%), allergy list (2%), problem list (1%) and immunization list (1%).

To further inform our ongoing efforts to improve MyChildren's, we are in the process of formally surveying all MyChildren's users to evaluate user satisfaction, ease of use and impact on access to and communication of health information. This survey is automatically sent to users via secure electronic message 90 days after their account is successfully activated. We also plan on conducting focus groups with select patient populations to address patient health information needs, as well as attitudes toward adoption of MyChildren's, and privacy concerns.

Conclusions

MyChildren's allows patients unique access to the benefits of a provider-tethered patient portal and an embedded PCHR. The challenges raised by the unique needs of a patient portal, a PCHR, and the pediatric and adolescent population require special attention in handling data feeds and setting appropriate policies to ensure easy and appropriate access, efficiency, patient privacy and confidentiality, as well as confidence in the reliability of the data contained in the record.

While the initial deployment has been encouraging, we are continuing to explore prospects for additional data feeds to the PCHR, including feeds from pharmacies, primary care providers, other health care institutions, and additional laboratories. A data feed from the Department of Public Health (DPH) has already been established, and we are in the process of leveraging this link to create additional functionality. Several applications currently exist as a research prototype, including an immunization decision support tool linked to the DPH, and an application that engages patients as collaborators in genomic discovery. These applications will be rolled out and made available in the near future, allowing patients and their guardians a more active role in managing their health.

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